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Symptoms in 400 patients referred to palliative care services: prevalence and patterns

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The demographics and prevalence of symptoms in patients at first referral to the different components of palliative care services were identified by a retrospective case note study of 400 patients referred to three palliative care centres in London, UK: Michael Sobell House, Mount Vernon Hospital; The North London Hospice; St Bartholomew's and the Royal London Hospitals. One hundred consecutive referrals to each of the following service components were analysed: a hospice inpatient service; a community team; an NHS hospital support team and an outpatient service. A standardized proforma was used to collect the data. Ninety five per cent (380/400) of patients referred had a cancer diagnosis. The five most prevalent symptoms overall were pain (64%), anorexia (34%), constipation (32%), weakness (32%) and dyspnoea (31%), which is similar to other published reports. However, the commonest symptoms and their prevalence varied depending on the service component to which the patient was referred. Patients referred to hospice and community services had the highest symptom burden (mean number of symptoms per patient 7.21 and 7.13, respectively). This study suggests that different patient subgroups may have different needs in terms of symptoms, which will be relevant for the planning and rationalization of palliative care services. *Palliative Medicine* 2003; **17:** 310–314

Key words: cancer; palliative care; prevalence; symptom burden; symptoms

Introduction

Cancer is a major cause of death in the UK. One in three of the population will develop cancer at some stage in their lives and one in four will die of the disease.[1] It is also a major cause of morbidity as distressing symptoms may occur due to the disease process itself, during treatment, or due to lack of adequate symptom control.[2]

Improving cancer and specialist palliative care services have been recognized as central priorities for the NHS.[1,3] Knowledge of the prevalence of symptoms is important for the medical care of all patients. Identification of symptoms is prerequisite to making diagnoses and therefore formulating management plans. Awareness of the relative prevalence of symptoms contributes to the identification of patients' needs in terms of symptom control, and therefore to the rational provision and planning of cancer and palliative care services.

Existing studies have looked at symptom prevalence in various populations of patients, ranging from hospitalized patients,[4] patients with advanced cancer,[5] those attending pain clinics[6] or those patients with a particular cancer diagnosis.[7,8] Other studies have determined the symptom prevalence of patients referred to a single palliative care service component: hospital palliative care teams,[9] hospice/inpatient palliative care units,[10–12] or community palliative care teams. [3–15]

A study which compares symptom prevalence in patients referred to the various components of a palliative care service has not yet been reported. Analysis of such data would be useful in the planning of these services as well as supporting healthcare professionals that refer patients to specialist palliative care teams for symptom control. Ultimately this would focus care and improve symptom control in all patients with progressive disease.

Study aims

The aims of this study are:

- To describe the demographics and prevalence of symptoms in patients referred to different components of palliative care services: inpatient unit/hospice; inpatient hospital support team; community team and outpatient clinic.

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- To identify any relationship between the different components of palliative care service provision and type or number of symptoms suffered.

Methods

A retrospective case note review of 400 consecutive referrals to three palliative care centres in London, UK was undertaken. The centres were: Michael Sobell House, an NHS palliative care unit based on the site of Mount Vernon Hospital, a cancer centre; The North London Hospice, an independent hospice; St Bartholomew's and the Royal London Hospitals (collectively named Barts and the London NHS Trust), a cancer centre and an acute teaching hospital, respectively. The first 100 referrals in the year 2000 to each of the following palliative careservices were analysed:

- Patients referred to a hospice inpatient unit (Michael Sobell House)
- Patients referred to a community team (The North London Hospice)
- Patients referred to an NHS inpatient hospital support team (Mount Vernon Hospital; Barts and the London NHS Trust)
- Patients referred to outpatient clinics (Michael Sobell House; Barts and the London NHS Trust)

A standardized proforma was developed for the study. A potential list of symptoms was compiled, combining information from previously published reports on symptom prevalence[4–15] and clinical experience. From the available literature the authors reviewed symptom terms, synonyms and definitions, and an initial list of 26 symptoms or symptom groups was compiled. The methods of grouping some symptoms (for example, 'urinary symptoms' is the symptom group term devised to include dysuria, urinary incontinence and frequency) were pragmatic and followed rationale used in other studies of symptom prevalence.[6]

Other demographic data collected on the proforma included age, sex, primary diagnosis, presence or absence of metastatic disease, and the site of referral (hospital or community). A pilot study of 60 patients (in four groups of 15 patients referred to each service component) assessed the utility and comprehensiveness of the data collection proforma.

Only one further symptom, dyspepsia, was added to the final proforma, as the pilot showed that this symptom occurred frequently. The total number of symptoms listed was 27.

Data were collected retrospectively from patient notes and symptoms recorded on the first clinical assessment were documented on the proforma.

The data were inputted in to the SPSS version 10.01 and statistical analysis was carried out using the chi-squared test. For data analysis involving multiple comparisons, the acceptable level of significance was reduced to $P < 0.01$.

Results

Of the 400 patients whose case notes were reviewed, 51% were male, and the mean age was 66 years (range 12–95 years).

Five per cent of patients had a noncancer diagnosis. Of the patients with cancer 71% had advanced disease. The most common cancer diagnoses were gastrointestinal (22%), lung (20%), genitourinary (19%) and breast cancer (13%). There was no difference in the age, sex or most common cancer diagnosis distribution between any of the subgroup populations.

Table 1 shows the prevalence of symptoms in all four groups. Overall, the five most prevalent symptoms were pain (64%), anorexia (34%), constipation (32%), weakness (32%) and dyspnoea (31%). The differences in prevalence between groups were strongly statistically significant for the symptoms of anorexia, constipation, weakness and dyspnoea ($P < 0.001$). Furthermore, the top five symptoms were not the same in each of the four subgroups (Table 2).

The symptom burden per group (mean number of symptoms per patient) is shown in Table 3. The hospice and community populations had the highest symptom burden, with means of 7.21 and 7.13, respectively.

Discussion

The demographic characteristics of patients in this sample are similar to those found in other studies.[9,10,13] Five per cent of patients had nonmalignant conditions. This underlines the predominance of palliative care services' involvement with patients who have malignant disease. The cancer diagnoses identified is similar to previous reports.[16]

The most prevalent symptoms overall were pain, anorexia, constipation, weakness and dyspnoea. This finding is comparable with other studies.[4,11] The proforma used included a checklist of 27 symptoms or symptom groups. A wide range of symptoms was found in each group of patients: of the 27 items listed in the proforma, 27 were identified in patients referred to the community, 26 in those referred to inpatient units, 24 to outpatient clinics, and 22 in patients referred to the hospital advisory team. The checklist was comprehensive and its use in this study has generated epidemiological

Table 1 Prevalence of 27 symptoms in 400 patients referred to palliative care services

	% Referrals with symptom				
Symptom	All% (n = 400)	Hospice% (n = 100)	Community% (n = 100)	Hospital% (n = 100)	Outpatient% (n = 100)
Pain	64	62	56	63	75
Anorexia*	34	58	56	6	17
Constipation*	32	52	35	22	17
Weakness*	32	41	73	5	10
Dyspnoea*	31	50	41	18	13
Nausea	29	37	34	25	18
Neuropsychiatric	27	39	28	28	11
Tiredness	23	24	42	7	18
Weight loss	18	12	46	3	10
Low mood	16	10	27	10	15
Vomiting	16	24	5	22	13
Dry mouth	16	31	26	2	5
Cough	15	30	18	8	5
Dermatological	14	35	16	0	7
Urinary	14	19	29	2	5
Anxiety	13	15	17	7	13
Oedema	12	18	14	3	13
Sleep problem	12	22	24	0	2
Loose stool	10	10	17	5	6
Dyspepsia	8	14	8	0	8
Numbness/tingling	8	9	18	1	5
Dysphagia	7	11	8	3	5
Haemorrhage	6	4	7	9	5
Early satiety	4	1	12	3	0
Sweating	3	5	2	0	4
Hiccoughs	2	0	6	1	0
Taste change	2	1	6	0	0

*Statistical significance of symptom prevalence between the groups: $P < 0.001$

data concerning symptoms that have not been found in the literature previously.

There were no significant differences in age, sex or type of malignancy, whether patients were in the community, in hospice or seen at outpatient departments. There were, however, marked differences in symptom prevalence and symptom burden between patient groups. There are several factors that may explain these phenomena.

Whilst the diagnostic mix was similar across the subgroups, the stage of disease was not: 28% of hospital inpatients, 26% of hospice inpatients, 12% of home care patients and 47% of outpatients did not have advanced disease. There is some evidence that symptom prevalence varies with tumour type,[17] and that the prevalence of pain[18] and anorexia[19,20] increases with tumour stage. However, other reports suggest that symptom prevalence is independent of the stage of disease.[21] In this sample the percentage of patients with advanced disease was similar in the hospital and the hospice inpatient groups, but the five most common symptoms were different. It is therefore unlikely that the difference in symptom prevalence can be fully explained by stage of disease.

Differences in symptom prevalence may simply reflect differences in data recording in each group. The data in this study is subject to any variability in quality, comprehensiveness and uniformity of note taking by four palliative care teams. The extent to which patients' symptoms were volunteered or elicited is unknown. Further, it is impossible to ascertain whether all symptoms identified were recorded in the notes. Patients were assessed in many different settings and this may also affect data recording. For example, outpatient consulta-

Table 2 Top five symptoms per palliative care service

Symptom ranking	Hospice	Community	Hospital	Outpatient
1	Pain	Weakness	Pain	Pain
2	Anorexia	Pain Anorexia (equal 2nd)	Neuropsychiatric	Nausea
3	Constipation	Weight loss	Nausea	Tiredness
4	Dyspnoea	Tiredness	Constipation Vomiting (equal 4th)	Anorexia Constipation (equal 4th)
5	Weakness	Dyspnoea	Dyspnoea	Low mood

Table 3 Symptom burden per group

Palliative care setting	Mean number of symptoms per patient
All	5
Hospice	7.21
Community	7.13
Outpatients	3.37
Hospital	2.7

tions may be shorter than other types of consultations, and this may result in a distillation of patients' problems down to those that are causing particular concern. This may explain the high prevalence of pain in patients referred to outpatient clinics and relatively lower prevalence of all other symptoms compared to other subgroups. However, the range of symptoms recorded in outpatient consultations is of similar magnitude to those recorded in other subgroups, suggesting that patient assessments in all settings were of a similar comprehensiveness.

Variable symptom prevalence and burden between groups may be, in part at least, explained by patients' circumstances at time of referral. For example, neuropsychiatric symptoms (including confusion, agitation and seizures) were the second most common symptom encountered in patients referred to hospital advisory teams.

This symptom group was the 6th, 10th and 11th most common symptom group encountered in inpatient unit, community and outpatient settings, respectively. It is possible that such symptoms are more apparent in a busy ward setting than, for example, in the patients' own home environment.

Lastly, the difference in symptom mix and prevalence may be explained by variability in data recording, factors surrounding site of patient at time of referral and different expertise of referring professionals. This study was not powered to differentiate any relative effects of these factors, but it may be that all three have a role. Constipation, for example, was found to be present more often in patients referred to inpatient hospice services and community services (52% and 35%, respectively) than in patients referred to hospital advisory teams or outpatient services (22% and 17%, respectively). It is possible that healthcare workers referring to these latter two services are more experienced at treating constipation, or that this symptom is not volunteered or specifically asked about in these two settings.

Conclusions and future recommendations

This comparative study has shown that symptom prevalence varies between the different palliative care settings. This variance does have implications for the organization of services. For example, the high prevalence of weakness in the community suggests that the provision of supportive services such as physiotherapy and occupational therapy may be particularly useful for this population. Likewise the frequency of neuropsychiatric symptoms in the hospital setting suggests that close working with colleagues in psychiatry may be advisable, or indeed that where possible, palliative care patients should be managed in the home or hospice environment rather than moved to an acute location.

Further studies are recommended. Ideally they should be of prospective design and incorporate a comprehensive checklist of symptoms. In addition, the severity of each symptom should be graded, and those symptoms recorded should be uniformly volunteered by, or elicited from, patients. This will eliminate possible confounders and bias. More information regarding the source of patient referrals would be useful. The results of such studies would contribute to rational planning of services, act as an audit tool for teams, and aid the identification of continuing educational needs of palliative care teams and those referring patients to them.

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